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THE MR FAMILY SUBSIDY PROGRAM: ITS EFFECTS ON FAMILIES WITH A MENTALLY
HANDICAPPED CHILD

A Report of a Survey

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In cooperation with the Developmental Disabilities Program and the Minnesota
Department of Public Welfare.

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It is extremely heartening to be able to report on a program illustrative of the kind of government intervention in family life that the MR Family Subsidy Program represents--the very best. I hope the study in some small way helps to bring about a more positive regard for the positive role that government can and often does play in the lives of families.

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SUMMARY OF MAJOR FINDINGS

1. The MR Family Subsidy Program greatly enables families to care for their mentally handicapped child at home.
2. The subsidy as a resource helps families to a great or very great extent.
3. The subsidy positively affects the capacities of families to function and cope with the care of their mentally handicapped child to a great or very great extent by enabling them to (in order of descending frequency):
 - . purchase special items needed by the child
 - . attend to the child's needs
 - . purchase respite care and babysitting services for the child
 - . do things outside the home they enjoy
 - . do things with family members
 - . enjoy each other's company as a family
 - . be with friends occasionally
 - . attend to the needs of family members
4. Dimensions of family functioning on which the subsidy has had the least effects include:
 - . enabling mothers to work outside the home
 - . enabling mothers to do things at home they enjoy
 - . enabling mothers to keep up with household chores
5. Dimensions of family functioning on which the subsidy has had the greatest effect include:
 - . the purchase of special items needed by the child
 - . the purchase of respite care and babysitting services
 - . attending to the needs of the mentally handicapped child
6. Families rate subsidy purchased services very highly, higher than services they receive from community agencies or family members and friends.
7. Almost none of the families presently plan to place their mentally handicapped child out of the home in long term care, but one half the families (N=19) indicate they anticipate doing so in the future.
8. Variables enhancing the subsidy's effects on family functioning are: ages of oldest, youngest, and mentally handicapped child; developmental progress of mentally handicapped child; length of family participation in the Subsidy Program; number of recent disruptive family life events; family resources; and family economic environment. With regard to family resources and family economic environment, there is an inverse relationship between these variables and the subsidy's coping effects.

9. The severity of the handicapping condition of other children in the family has a dampening effect on the coping effects of the subsidy on families, $r = -.92$, although the small number of families to which this variable applies precludes drawing firm conclusions about its effects.
10. Families with older mothers, mothers who do not work outside the home, and with more children are less likely to anticipate the long term out of home placement of their mentally handicapped child than families with younger mothers, mothers who work outside the home, and with fewer children. Families in which the mentally handicapped child shows more developmental progress are less likely to anticipate long term out of home child placement than families in which the child shows less developmental progress. These findings are independent of the positive effects of the subsidy on family functioning and coping capacities.
11. Almost all the families think the Subsidy Program should be expanded to include young adults.
12. The linkage role of the social worker with respect to families and the MR Family Subsidy Program is critically important but sometimes problematic. This suggests the need to develop and open multiple channels of communication through which information about the Program can flow to families with a severely mentally handicapped child.
13. Although the findings are highly suggestive, because of the small N (38) on which they are based, caution should be exercised in generalizing about them beyond the study's sample.

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The provision of financial incentives and home based services to enable families with handicapped members to care for such members in their own homes and thus prevent or forestall their out of home placement in foster homes or institutions is a fairly recent policy development. It emerged in part as a response to the spiraling costs of out-of-home placements and in part to a heightened awareness of the service functions that families in fact perform for their members. The effectiveness of financial incentives and home based services currently is being demonstrated and tested in a number of counties throughout the state by both voluntary and public agencies in relation to a variety of family situations.

The MR Family Subsidy Program, launched in 1976 by the Minnesota Department of Public Welfare, is representative of such efforts. The Program is designed for families of children under age 18 with a primary diagnosis of mental retardation who either are living at home, or in a state institution or licensed community residential facility, and who because of the Subsidy Program, could remain in or return to their own homes. Priority is given to families of severely and multiply handicapped children who are experiencing a high degree of family stress and show the greatest potential for benefitting from the Program. Although the Program is for children with a primary diagnosis of mental retardation, such a requirement has been more liberally interpreted to include children who are functionally retarded as well, such as autistic children and children who are emotionally or mentally ill.

Initially, the Program included only 50 families, but in the last year it was expanded to include 187 families throughout Minnesota. The average monthly subsidy per family is \$245.00 with the maximum set at \$250.00. Such monies are above and beyond other provisions families may receive in the community and are to cover expenses for such needs as respite care, special equipment, special clothing, family counseling, camp, medical and dental care, and so forth, arising as a consequence of the child's disability. Because many families in the Program are users of other community services and programs, the MR Family Subsidy Program is designed to complement, not duplicate, them.

The questions this study seeks to explore are: what are the coping effects of the MR Family Subsidy Program on families with severely mentally handicapped children participating in the Program? What family, environmental, and resource variables serve to heighten or dampen such effects? And does their influence extend to the long term care plans of participating families for their children? These questions will be approached from the perspective of family stress and coping within systems and developmental frameworks.

SIGNIFICANCE OF THE STUDY

Life presents difficulties for almost all families. Such difficulties are stressors that each family defines for itself in terms of the hardships or burdens it experiences (Hill, 1958; McCubbin & Patterson, 1981; Darling, 1981). A stressor is considered a life event, occurrence or situation that creates change in the family as a social system. For some families, the birth or care of a severely mentally handicapped child

may be such a stressor, changing the ways in which family members interact with one another, their value priorities, their goals as a family, the quality of their relationships to one another, the ways in which they allocate and perform family roles, and the boundaries that serve to define them as a family.

Most families experience many stressors simultaneously, including-- or especially--families with mentally handicapped children. Some of these stressors are normative and internally induced in terms of individual and family life cycle changes and role transitions, such as when younger brothers and sisters enter kindergarten while the older mentally handicapped sibling remains at home; others are non-normative but also internally induced as, for example, when an angry and resentful parent physically abuses his or her mentally handicapped child because of the way the parent interprets the child's condition; still others are environmental and externally induced, as illustrated when a depressed economy forces parents of mentally handicapped children into unemployment, or the failure of communities to provide such needed resources or services as special education programs for mentally handicapped children, or respite care for their families, or information about the MR Family Subsidy Program to those families who may be eligible for it. McCubbin et al (1981) have aptly labeled the accumulation of such stressors as "stress pile-up." Such stressors create stress for families when the demands they place on families exceed the capacities of families to cope with them, coping referring to the ability of families and their members to act in ways that alleviate stress by drawing upon resources from both within themselves and from their external environment.

Objectively, the care of a severely retarded child has been found to be a burden or hardship for families on many dimensions, such as time, money, physical and emotional energy (Willer, Intagliata, & Wicks, 1981) for which the State of Minnesota is willing to partially compensate them, as illustrated by the Subsidy Program. However, each affected family subjectively interprets and defines the hardships or burdens or stressors such care may impose on it in light of its own values, previous experiences and present circumstances, which include the psychological and physical well-being of individual family members, such family characteristics as size, composition, socio-economic status, and the internal and external resources upon which it can draw. Thus some families may view the care of a severely mentally handicapped child a greater burden or hardship than others and the Subsidy Program a more important resource in helping them manage or cope with their situation.

Because of the increasing emphasis on the home care of handicapped and chronically ill populations by their families, the questions this study seeks to examine: what are the coping effects of the MR Family Subsidy Program on families with a severely mentally handicapped child and what family, environmental and resource variables serve to heighten or dampen such effects, have both practical and theoretical significance beyond the Program itself. Family variables, often found to shape the outcomes of public programs in unconsidered ways, are seldom taken into account in Program design, implementation, or evaluation, thus often leading to erroneous conclusions and interpretations regarding program

impact. By explicitly including such variables, this study attempts to redress this serious oversight.

Specific family variables examined in relation to the study's dependent variables, the coping effects of the MR Family Subsidy Program on families with a severely mentally handicapped child and their plans for the child's long term care, include: 1) family size, structure, and composition; 2) family life cycle stage; 3) socio-economic status; 4) family health status; 5) internal family supports and resources; and 6) recent family events, identified in the literature as stress producing (Holme and Rahe, 1967). Resource variables examined relative to the dependent variables include the size of the subsidy individual families receive, the length of time they have received the subsidy, as well as other kinds of resources and services available to them. Environmental variables examined in relation to the dependent variables include the population and economic well-being of the communities in which families reside, the number of mentally retarded persons living in the communities in which families reside, and community attitudes towards mentally handicapped persons. The latter variables have been identified as being influential in presenting environmental challenges to policy makers (Eulau and Eyestone, 1968). When such challenges give rise to "problems" and these come to the attention of policy makers, policy makers may be willing to pursue policy and program development in a given area, such as the development of community resources and services for mentally handicapped children upon which their families may be able to draw to help them cope with their situation.

MEASURING THE VARIABLES

The Dependent Variables: Subsidy's Coping Effects and Families' Long Term Care Plans for Children

Several measures were used to assess the coping effects of the MR Family Subsidy Program as a resource for families with severely mentally handicapped children, the study's major dependent variable, each focusing on slightly different aspects. One measure pertained to the extent to which the Program enables families to care for their mentally handicapped child at home; another pertained to the degree to which the Program is helpful to families; a third pertained more specifically to the ways in which and the extent to which the program enables families to cope and function, socially, psychologically, and financially; and a fourth pertained to changes in family coping and functioning that could be attributed to the Program.

Specific coping dimensions measured included the respondent's ability to: 1) keep up with household chores; 2) purchase special services or items needed by the mentally handicapped child; 3) hire babysitters or purchase respite care; 4) work outside the home; 5) do things with other children in the family or spouse; 6) enjoy the company of family members; 7) do things at home, such as sewing, cooking, gardening, for fun; 8) do things outside the home, such as going to movies, walking, etc; 9) be with friends occasionally; 10) attend to the needs of the mentally handicapped child; 11) attend to needs of other family members. Responses to all of the coping effects measures were ordinaly scaled from one to five, one being to absolutely no extent and five being to a very great extent. Change in

family functioning as a consequence of the Subsidy Program was measured by questions asking about the same coping dimensions conceptualized in before and after Subsidy terms.

To measure and ascertain families' plans for the long term care of their mentally handicapped child, another dependent variable, a nominal level yes-no question was asked regarding 1) families' present plans to place their child out of the home for long term care in a foster home or institution, and 2) their future plans for doing so.

The Independent Variables

Family Variables: Family Size, Structure, Composition, Life Cycle Stage

Several questions were used to measure the family variables. Family size, structure, and composition were measured by questions asking about respondents' marital status with five coded response possibilities:

1) married, 2) remarried, 3) divorced or separated, 4) widowed, or 5) never married; about the number of children in the family, including step children; about the number of parents living at home; and the number of boys and girls in the family, including the gender of the mentally handicapped child. Family socio-economic status was measured by questions dealing with both mothers' and fathers' level of education: 1) less than high school, 2) high school, 3) some college, 4) BA degree, 5) some graduate work, 6) master's degree, 7) some post master's work, and 8) Ph.D. degree. Another question to measure family SES concerned approximate annual family income which was coded into nine response categories ranging from less than \$5,000 up to \$30,000 in \$5,000 increments and then in \$10,000 increments up to \$50,000 and over.

Family life cycle stage was measured in terms of parents' ages and ages of youngest and oldest child in the family. Parents' ages were grouped into nine age categories ranging from less than 20 years up to 50 years in five year increments and in a 10 year increment from 51 to 60 with age 60 and over left open ended. In terms of children's ages, age response categories for the oldest child, ranging from birth to 40 years and over, were grouped into nine life cycle stages: 0-1, infancy; 2-4, pre-school; 5-9, school age; 10-12, pre-adolescence; 13-17, adolescence; 18-21, young adulthood; 22-29, mid to late young adulthood; 30-39, young middlehood; 40-plus, mid-middlehood. Age response categories in terms of the youngest child in the family were similarly grouped, ranging more narrowly from infancy to young adulthood. A similar question was asked pertaining specifically to the age of the mentally handicapped child to determine his/her ordinal position within the family structure.

Family Stressors: Family Health, Severity of Child's and Other Children's Handicapping Condition, Family Life Events

Family health status was measured by three questions, one pertaining to the overall health status of mothers, one to the overall health status of fathers, one to the overall health status of children other than the handicapped child, with ordinally coded responses of: 1) very poor, 2) poor, 3) fair, 4) good, and 5) excellent. In addition, a yes-no question was asked to ascertain whether other children in the family, in addition to the mentally handicapped child for whom the family receives a subsidy, have a handicapping condition. For those who responded yes, the question was followed by a series of questions concerning the effects

of the child's handicapping condition on his or her ability to toilet him/herself, walk, see, hear, play with other children, and relate to adults. These questions were ordinally scaled from one to five, one being to no extent and five to a very great extent. A similar set of questions was asked and similarly scaled pertaining to the mentally handicapped child.

Additional questions designed to measure other stressors on the family consisted of a series of yes-no questions coded 1 for yes and 0 for no, pertaining to family life events experienced by families in the last six months, such as a death in the family; a serious illness; job loss; divorce or separation; birth of a child; remarriage; adoption of a child; large loss of income; large increase in income; a serious disability; difficulty with the law; and the institutionalization of a family member, events previous studies have identified as being stressful for families (Holmes & Rahe, 1967). Another stressor measure pertained to the degree of difficulty families experienced in meeting expenses not covered or not completely covered by the subsidy relative to the care of the mentally handicapped child; the question was ordinally scaled from one to five, one being not at all difficult and five being very difficult.

Finally, to obtain a measure of the child's development as another potential stressor, respondents were asked to indicate, yes or no, if he or she had progressed faster than what might have been expected without the subsidy on four dimensions: social, physical, intellectual, and emotional. Yes responses were coded 1 and no responses were coded 0.

Family Resources and Supports: Family, Community & Subsidy

The availability of other supports or resources to assist families in coping with the care of their mentally handicapped child, in addition to the subsidy, was measured in several ways. One set of questions attempted to determine those family members who assume the most and least responsibility for the care-taking role vis-a-vis the child, besides the mother. Coded responses for both were framed in relation to the mother, such as spouse, maternal and paternal parents, daughter, son, maternal and paternal siblings and family friend. If the response was a daughter or son, respondents were asked to indicate the ordinal relationship of the sibling to the mentally handicapped child, that is, whether he or she is younger or older than the mentally handicapped child.

Another series of questions measuring supports or resources available to families in the study pertained to the degree of help families receive in caring for their mentally handicapped child from fourteen identified sources, such as maternal and paternal parents, children, maternal and paternal siblings, family friends, and community agencies, such as the county welfare department, mental health center, public school, day activity center, state hospital, and religious organizations, such as churches or synagogue. Responses to the series were ordinally scaled from one to five, one being to no extent, and five to a very great extent. To measure respondents' evaluations and perceptions of Subsidy purchased services and services they receive from family members and friends, and community agencies, respondents were asked to

rate such services in terms of their 1) quality, 2) availability, 3) accessibility, 4) convenience, and 5) cost. Again coded responses were ordinally scaled from one to five, one being very poor and five being excellent. Separate questions regarding family use and perceived helpfulness of counseling services and respite care were asked to obtain specific resource measures on them with respect to the study's families.

Subsidy variables were measured by questions pertaining to the amount of the subsidy families receive, the length of time they have received the subsidy measured in years, the length of time they waited before being able to participate in the Program measured in months, and the mechanism that linked them to the Program. Coded responses for the latter question included social worker, friend, family member, newspaper article, other families in the program, Association for Retarded Citizens, word of mouth. Additional questions about the Subsidy Program concerned families' opinions regarding the expansion of the Program to include young adults.

Environmental Variables

Environmental variables, such as the size and economic well-being of the county in which families in the Program reside were measured by county population in 1980 and median annual income per county tax filer in 1980. Community attitudes toward mentally retarded persons were measured by the proportion of beds in the county available for mentally retarded wards while the number of mentally retarded wards living in the county served as a measure of the size of the political constituency for mental retardation programs and services in the county.

DESIGN AND METHODOLOGY

Survey Sample, Data Collection Procedures and Response Rate

To obtain the foregoing information, a telephone survey was conducted of a stratified sample of 70 families currently participating in the MR Family Subsidy Program, representing almost 37 percent of the Program's families. The sample was stratified on two dimensions: the county in which families reside and the year in which they came into the Program, as a way of assuring statewide representation of participating families and representation by the length of their Program participation. Within these two dimensions, families were randomly selected proportionate to their representation in the Program. Sample selection was carried out by the Supervisor of the MR Family Subsidy Program who randomly selected six families from the years 1976 to 1978, 29 from the years 1979 to 1980 and 35 from the years 1981 to 1982, suggestive of the growth in the Program since its inception. In terms of county representation, 15 families were selected from Hennepin, 7 from Ramsey, 4 from Anoka, 3 each from Blue Earth, St. Louis, and Carver counties, 2 each from Crow Wing, Stearns, Becker and Mower, and 1 each from Brown, Benton, Beltrami, Carlton, Cass, Dakota, Douglas, Freeborn, Goodhue, Houston, Kandiyohi, Lake, Lincoln, Meeker, Marshall, Nicollet, Otter Tail, Olmstead, Pipestone, Rice, Renville, Red Lake, Steel, Todd, Wadena, Winona, and Wright. Thus all of the counties in which participating families reside were represented in the sample.

A letter was sent to the parents of the 70 randomly selected families inviting them to participate in the study and explaining its nature and purpose. The letter was written by the Supervisor of the Mental Retarda-

tion Family Subsidy Program on Minnesota Department of Public Welfare letterhead stationary (see Appendix A). The letter identified the two cooperating agencies, the Developmental Disabilities Program and the Minnesota Department of Public Welfare, and the Project Director. It explained how families were selected for the study, how the study would be conducted, and the approximate length of time the telephone interviews would take. In addition, the confidential nature of individual responses and the voluntary nature of participation in the study were assured, buttressed by the assurance that the program status of individual families would not be jeopardized if they chose not to participate in it. A voluntary consent form was included with the letter which the primary caretaker was asked to sign and return to the Project Director to indicate the family's willingness to participate in the study, noting time and day of the week the family preferred to be interviewed (see Appendix B).

With the exception of only one, all forms were signed by mothers as the child's primary caretaker who was designated in the letter as the person with whom the interviews would be scheduled. The one form not signed by a mother was signed by a grandmother who is the child's primary caretaker in a family in which the mother recently died. In all, 43 consent forms were returned which represented approximately 61 percent of the selected sample. Five of these consent forms were rejections, however, so that the actual number of families who participated in the study was 38, representing 54 percent of the selected sample. Although such a response rate represents over half the selected sample and indeed is quite high for a mailed invitation, indicating substantial

interest on the part of the contacted families in the study, the small N means that caution should be taken in generalizing the findings to the study's population. A follow-up letter urging remaining families to return their consent form was not considered advisable by the Program's staff and time constraints did not permit consideration of expanding the sample to include additional families not included in the initial sample. Both time and financial constraints precluded surveying the entire population of Subsidy Program families which would have been the most desirable of all the sampling alternatives.

A pretested precoded structured questionnaire with 177 items was developed to conduct the survey (see Appendix C). To minimize redundancies in the conduct of the interviews, questionnaire items scaled from one to five purposely omitted intervening scale points in their wording. However, such scale points were carefully defined in the subsequent training of the survey's interviewers. Four open ended questions whereby participants could articulate their responses in their own words and style were included at the end of the questionnaire to allow for response flexibility and also as reliability and validity checks. Such questions asked respondents what they liked best and least about the program, their suggestions for improving the program and what they would do with a larger subsidy if it were available to them.

Two interviewers were hired to conduct the survey; both had prior experience in conducting interviews or in working with people in a professional capacity. During a two hour training and orientation session, the interviewers were familiarized with the study's purpose and the MR Family Subsidy Program. To make sure each of the interviewers

understood the questions in the form in which they were written and also to assure the proper coding of responses, each interviewer was given an opportunity to conduct a practice interview and code the questionnaire. Intervening scale points omitted in the questionnaire were ordinarily defined during the orientation session for items asking about the extent to which the subsidy has helped families cope with the care of their mentally handicapped child, one having been defined to absolutely no extent and five to a very great extent in the questionnaire. Thus two was defined as being to a small extent, three to some extent, and four to a great extent during the orientation session. Written instructions were provided outlining the nature of the study, explaining the MR Family Subsidy Program, the manner in which the interviews were to be conducted, the coding of questionnaire items with the various phone numbers of the project director listed in the event of unanticipated problems or questions that might arise during the conduct of the survey (see Appendix D). Apparently few problems arose since the project director was contacted only once during the interview period. Interviews took approximately one half to an hour to complete; all interviews were completed within five weeks from the time they began.

Information pertaining to environmental variables of county size, income, numbers of mentally retarded persons living in the county, and number of beds for mentally retarded persons in the county, the latter two variables being measures of the political constituency for programs for mentally retarded persons and community attitudes toward mental retardation respectively, was obtained from public records through the Minnesota Department of Public Welfare.

Data Analysis

Percentages and means were used to examine response differences on the several rating scale items; open ended responses were content analyzed. Pearson's R was used to examine the relationship between the dependent variable, the coping effects of the MR Family Subsidy Program on families participating in the program, and the study's several independent variables. In addition, two sample t tests were performed on the placement plans of families for their mentally handicapped child relative to variables initial analysis suggested might be operative.

To facilitate the data analysis, several sets of related items were summed and averaged to obtain indices. For example, a family health score was created by summing and averaging the individual ratings of mothers', fathers', and children's health status ratings. The same procedure was used to obtain a handicapping condition score for both the mentally handicapped child for whom the family receives the subsidy and other children in the family with a handicapping condition. Similarly, a family functioning and coping score was obtained by summing and averaging respondents' ratings on the 11 coping dimensions measured in the study, both in terms of families' present ability to cope and their ability to cope before receiving the subsidy. The former was labeled family functioning score I; the latter was labeled family functioning score II. To obtain a change score in family functioning that could be attributable to the Subsidy Program, family functioning score II was subtracted from family functioning score I.

A family resource score was obtained by adding and averaging respondents' ratings on the extent to which they receive help from the 14 identified family and community resources in caring for their mentally handicapped child. An evaluation score was obtained for subsidy purchased services, for services provided by family and friends, and for services provided by community agencies by adding and averaging respondents' ratings on five measured dimensions: quality, availability, accessibility, convenience, and cost.

A family life events score was obtained by summing the yes responses for each life event families experienced in the last 6 months just as a progress score was obtained for the mentally handicapped child by summing the yes responses for each of the developmental dimensions on which he or she has progressed since his or her family first received the subsidy.

The study's variables and composite indices represent a mix of ordinal and interval level measurements. Some interval level measurements, such as age and income, which included unequal intervals, could be problematic in some studies but were not considered problematic in this study since the attempt was to obtain an ordinal ranking of these measures rather than their precise measures. Although some readers may regard Kendall's tau as more appropriate for the level of measurement of some of the variables, Blalock (1972) advises that Kendall's tau yields relationships similar or identical to Pearson's R. Pearson's R was used in the data analysis because according to Kerlinger (1973), parametric statistics, such as Pearson's R, are more discriminating than non-parametric statistics such as Kendall's tau.

THE FINDINGS

The Families of the Mentally Handicapped Child: Family Size, Structure, and Composition

Of the 38 families participating in the study, almost all, 95 percent, are families of two never divorced or separated parents living with their first spouse and children. In only five percent of the families (N=2) are parents divorced or separated. Except for three families in which the mentally handicapped child is an only child, all the others have two or more children. Five families each have as many as four and six children while one family has as many as five and another as many as seven children. The modal number of children per family is two but the average is three. The number of children actually living at home ranges from one to six. Because almost all of the respondents are married to their first spouse and the only two who are divorced or separated have not remarried, none of the families involve step-parents or step-children requiring a rearrangement of family relationships based on changes in the persons occupying parental positions.

There are more boys in the study's families than girls. The modal number of boys per family is two (33 percent of the families, N=12), whereas for girls it is one (46 percent of the families, N=17). The number of boys per family ranges from none for 17 percent of the families (N=6) to five for six percent of the families (N=2), whereas for girls the number ranges from none for 14 percent of the families (N=5) to four for one family. Overall, there is a total of 68 boys and 54 girls represented among the families surveyed, or roughly about 20 percent more boys than

girls. The sex distribution of the mentally handicapped children among the families surveyed reflect a similar pattern in that 63 percent (N=24) are boys and 37 percent are girls (N=14).

Family Life Cycle Stage: Mothers, Fathers and Children's Ages

Mothers range in age from their late 20s to their 50s, most being in their 30s (60 percent, N=23), and a fairly sizable percentage being in their late 20's (24 percent, N=9), thus ranging from late young adulthood to mid-middlehood in life cycle terms. Fathers are in similar life cycle stages, ranging in age from their late 20s to late 50s, although as a group they tend to be about five years older than mothers, their average age category being 36-40 as contrasted with mothers' 31-35 average age category. Also they are more evenly distributed along the life cycle continuum with 11 percent (N=4) represented in the 26-30 age group, 22 percent (N=8) in the 31-35 age group, 31 percent (N=11) in the 36-40 age group, 17 percent (N=6) in the 41-45 age group, 14 percent (N=5) in the 46-50 age group, and a little less than six percent (N=2) in the 51-60 age group. None are over 60. By contrast, 24 percent (N=9) of the mothers are 26-30, 26 percent (N=10) 31-35, 34 percent (N=13) 36-40, eight percent (N=3) 41-45, five percent (N=2) 46-50, and only three percent (N=1) 51-60. Again none of the mothers are over 60.

The average age category of the mentally handicapped child is 5-9 years with 50 percent of the children being in this age group (N=19). By definition, the ages of the mentally handicapped children in the study range from pre-schoolers of 2-4 years of age (13 percent, N=5), to adolescents of 13-17 (11 percent, N=4) with 26 percent (N=10) being pre-

adolescents, 10-12 years old. By contrast, oldest children in the family tend to be pre-adolescent, as measured by their average age category, 10-12 (23 percent, N=8), but in terms of their modal age group they would be characterized as school age, 5-9 (29 percent, N=10). However, unlike the mentally handicapped children, the age span of oldest children extends from 2-4 years, or pre-schoolers, to 30-39 years or young middlehood (N=1), thus representing a wider age span which includes oldest children in late adolescence, 18-21 (11 percent, N=4), and young adulthood, 22-29 (11 percent, N=4). The ages of youngest children represents a much narrower age span from birth to infancy, 0-1 (20 percent, N=7), to adolescence, 13-17 years (three percent, N=1), with an average age category of 2-4 (31 percent, N=11). Their modal age category is 5-9 (34 percent, N=12). Thus, as measured by their average age groups, the mentally handicapped children tend to be somewhere in the middle in life cycle terms in relation to youngest and oldest children in the family, but as measured by age range they are more similar to youngest than oldest children. All three groups are the same in terms of their modal age group, 5-9.

Family Socio-Economic Status

In terms of family SES, as measured by parents' education and annual family income, the average level of educational attainment for mothers is high school, 53 percent (N=20), although 21 percent (N=8) have had some college with 16 percent (N=6) having completed college; only 11 percent (N=4) have less than a high school education. Although fathers are represented in each of the educational attainment level categories from less than high school (14 percent, N=5), to Ph.D. degree (3 percent,

N=1), and seven percent more fathers than mothers have had some college (28 percent, N=10), as a group their educational attainment level averages only a little higher than mothers. This can be explained by the fact that five percent fewer fathers than mothers have a BA degree (11 percent, N=4), even though no mother in the group has a master's or Ph.D. degree as do one of the fathers for each. Forty-two percent (N=15) of the fathers are high school graduates.

Family annual income for the study's families ranges from a low of \$5,000 or less to a high of \$40-49,000 with one family represented in each of these extreme income categories (three percent) as well as in the \$30-\$39,000 income category. Families are somewhat more evenly distributed in the middle income groups with 24 percent (N=9) in the \$10-\$14,000 income category, 21 percent (N=8) in each of the next two income quintiles \$15-\$19,000 and \$20-\$24,000. and 18 percent (N=7) in the \$25-\$29,000 income category. The remaining eight percent (N=3) have annual incomes of \$5-\$9,000. While the modal income quintile is \$10-\$14,000 (24 percent, N=9), the average income category is the next highest quintile, \$15-\$19,000 (21 percent, N=8).

All of the fathers in the study are employed, almost all full time, 94 percent (N=34). The remaining six percent (N=2) are employed part time. Mothers tend to be employed outside the home far less frequently. Of those mothers who do work outside the home, 26 percent (N=10) are employed part time and only 16 percent (N=6) full time. The rest, 58 percent (N=22), are full time homemakers.

Family Health and Severity of Child's and Other Children's Handicapping Condition

In general, the overall health of the study's families was reported to be good to very good with 97 percent (N=34) of the respondents reporting the health of children in the family, other than that of the mentally handicapped child, good to very good, and 92 percent reporting the same for themselves (N=35) and their spouses (N=33). Of the small number presenting a less positive picture with respect to their family's health, none gave a rating of less than fair for any member, even though 17 percent (N=6) indicated that at least one other child in the family in addition to the mentally handicapped child for whom the family receives a subsidy has a handicapping condition. Although the other child's handicapping condition does not greatly affect his or her ability to function independently in terms of seeing, hearing, or playing with other children in any of the families, it does affect his/her ability to walk and toilet him or herself, relate to adults and to function along other unspecified dimensions from a small to a very great extent.

In terms of the mentally handicapped child for whom the family receives a subsidy, the effects of the child's handicapping condition on his or her ability to function is severe. Over three-fourths (N=29) of the families reported the child's condition greatly affects his or her ability to toilet him or herself and play with other children, with a huge 93 percent (N=23) reporting that the handicapping condition also affects the child's ability for self-care, such as self feeding and dressing and in other unspecified ways. Almost 60 percent (N=22) reported the child's handicapping condition also greatly affects his or her ability to relate to adults while 54 per-

cent (N=21) reported it greatly affects the child's ability to walk. However, for most of the mentally handicapped children, their condition does not greatly affect their ability to see and hear, according to 62 percent (N=23) of the respondents. (See Table 1.)

 Insert Table 1 about here

Family Resources

In terms of the caretaking role different family members assume with respect to the mentally handicapped child, fathers assume this role more than any other family member besides the mother, according to 82 percent of the respondents (N=31). In the remaining 18 percent of the families (N=7), older children, regardless of sex, assume this role the most frequently. In families in which children do not play an important caretaking role with respect to the mentally handicapped child (77 percent, N=27), such children generally are younger than the mentally handicapped child (52 percent, N=15). Family members identified as assuming the least responsibility in helping to care for the child in descending order are the child's paternal grandmother (nine percent, N=3), fathers (six percent, N=2), the child's maternal grandmother, paternal aunt and maternal brother (3 percent in each case, N=1). Thus, in most families, fathers play the primary caretaking role in assisting mothers with the care of their mentally handicapped child while younger siblings assist the least.

Family and community resources identified by mothers as being most helpful to them with respect to the care of their mentally handicapped child in descending order include the public schools, 67 percent (N=25);

Table 1. Effects of Mentally Handicapped Child's Condition*

Effects	N	(1-2) none or small %	(3) some %	(4-5) great/very great %
toilet self	38	18	5	76
walk	38	34	11	55
see	37	62	11	28
hear	37	62	27	11
play with other children	38	8	16	76
relate to adults	38	13	29	60
other (self-feeding, dressing, self control, etc.)	25	--	8	92

*Percentages may not add to 100 because of rounding.

their children, 47 percent (N=16); the county welfare department, 35 percent (N=13); mothers' parents and the state hospital, 17 percent each (N=6); mothers' sister, 16 percent (N=5); parents-in-law and family friends, 11 percent each (N=4); the day activity center, 9 percent (N=3); sister-in-law, brother, and public health center, 6 percent (N=2); and lastly, brother-in-law, mental health center, and religious organizations, 3 percent each (N=1). Clearly, the most helpful community and family resources for the study's families are the public school, their children, and county welfare department. Although fathers were not identified as a resource in this series of questions, since they were identified by mothers as the family member who assumes the most responsibility in helping them care for their mentally handicapped child, it may be assumed that mothers, if asked, would have identified fathers as being the most helpful resource of all to them. The only exception would be the one or two mothers who indicated that fathers' jobs kept them from being more helpful and, of course, the two families in which fathers no longer are living at home. (See Table 2.)

Insert Table 2 about here

Family Life Events

The study's families did not seem to experience an unusually large number of family life events that could be viewed as stressful or disruptive during the last six months. A serious illness of a family member was the most frequently cited family life event experienced by the study's

Table 2. Extent to Which Identified Resources are Helpful to Mothers*

Resources	N	(1-2) none/small extent %	(3) some extent %	(4-5) great/very great extent %
Schools	37	11	22	67
Children	34	29	24	47
County Welfare Agency	37	54	11	35
Parents	36	58	25	17
State Hospital	35	80	3	17
Sister	31	77	6	16
Parents-in-Law	35	77	11	11
Friends	38	68	21	11
Day Activity Center	32	84	6	9
Brother	31	90	3	6
Sister-in-Law	35	89	6	6
Public Health Center	35	89	6	6
Religious Organization	38	84	13	3
Mental Health Center	33	94	3	3

*Percentages may not add to 100 because of rounding.

families, 19 percent (N=7), followed by a large drop in income for 16 percent (N=6) of the families which in turn was followed by a job change for 13 percent (N=5) and the loss of a job for 11 percent (N=4) of the families. Eight percent (N=3) experienced a serious disability which one family cited in connection with a serious illness. Although 11 percent of the families (N=4) experienced the leaving or return of a family member, only six percent (N=2) of the families experienced the loss of a member through death or divorce. At the same time, six percent (N=2), of the families added a member through birth or adoption. Although most families reporting changes in their economic situation reported such change in terms of income loss, one family reported it in terms of a large income gain. Only one family reported a member getting into trouble with the law, but apparently not to the point of incarceration since no one reported the institutionalization of a family member. Thus, the family events experienced by the study's families were primarily economic rather than structural in nature. (See Table 3.)

 Insert Table 3 about here

The MR Family Subsidy Program

It can be stated without equivocation that the study's families unequivocally regard the MR Family Subsidy Program of great or very great help (97 percent, N=37), with only three percent (N=1) rating its helpfulness a little less enthusiastically, as being of only some help, yielding an overall mean average helpfulness rating of 4.9 (s.d.=.39). Eighty-four

Table 3. Family Life Events Experienced in the Last Six Months by Program Families

Events	N	Number	Percentage
Death	36	1	3
Serious Illness	36	7	19
Loss of a Job	36	4	11
Divorce	36	1	3
Birth of a Child	36	1	3
Remarriage	38	0	0
Adopted Child	38	1	3
Return or Leaving of a Family Member	38	4	11
Job Change	38	5	13
Serious Disability	38	3	8
Loss of Income	38	6	16
Large Increase of Income	38	1	3
Trouble With the Law	38	1	3
Institutionalization	38	0	0

percent (N=32) stated the program has enabled them to care for their mentally handicapped child at home to a great or very great extent with only 13 percent (N=5) responding less enthusiastically "to some extent" and a negligible three percent (N=1) responding "to no extent." Indeed, one mother said that were it not for the subsidy, she would not be able to care for her child at home.

Families receive payments ranging from \$76 to \$250 per month with over two thirds (N=26) receiving the maximum allowable amount of \$250. Most of the families (49 percent, N=19) have participated in the program for less than two years, reflective of the program's recent expansion. Only a few families (10 percent, N=4) have participated in the program since its inception or very early years, from four to six years, while the remaining 39 percent (N=15) have participated in the program from two to three years. On the average, families waited two to six months after applying before receiving their first subsidy payment. Most learned about the program through their county social worker, 50 percent, but other program participants also were important sources of information for 16 percent (N=6) of the families. Only one family learned about the program from another family member.

Responses to probes into specific ways in which the MR Family Subsidy Program is helpful in enabling families to cope with the care of their mentally handicapped child are suggestive of the stress such care involves, financially, psychologically, and socially. For example, most families, 95 percent (N=36), stated the subsidy was of great or very great help in enabling them to purchase special items needed by the child, purchase baby-

sitter services or respite care, 71 percent (N=27); do things with other children in the family and their spouse, 58 percent (N=22); enjoy each other's company as a family 55 percent (N=21); do things outside the home, such as going to movies or taking walks, 61 percent (N=23); be with friends occasionally, 55 percent (N=21); attend to the needs of other family members, 55 percent (N=21); attend to the needs of the mentally handicapped child, 92 percent (N=35), all representing ways of coping with their situation and functioning as a family. One mother in her open ended comments elaborated by saying the subsidy has enabled her in particular to attend to the physical needs of her husband who has high blood pressure and a lesion on his kidney and behind his eyes, suggestive of stressor pile-up to which reference was made earlier (McCubbin & Patterson, 1981). Several referred to the financial and psychological security the program affords them, one referring to the sense of autonomy and freedom the program affords her, contrasting it with welfare programs such as AFDC.

This is not to say that the subsidy necessarily enables mothers to manage better on all counts, however. The subsidy, for example, does not necessarily enable mothers to keep up with household chores, 63 percent (N=24), nor work outside the home, 50 percent (N=14), nor do things at home, such as sewing, gardening, or cooking for fun, 50 percent, all activities that compete for their time, attention and energy. At the same time, mothers managed better along these latter dimensions after they received the subsidy than before. Indeed, 69 percent (N=18) said they did not work outside the home before receiving the subsidy as contrasted with the 50 percent (N=14) after, a shift of almost 20 percent.

A smaller, but directionally similar shift may be seen by the 53 percent (N=20) who said they were unable to do things they enjoyed at home before receiving the subsidy as contrasted with the 50 percent (N=19) after. It is only along the dimension of keeping up with household chores that the subsidy appears to have made little difference; 53 percent of the mothers (N=22) indicated they were able to keep up with household chores to a great or very great extent before receiving the subsidy as contrasted with 26 percent (N=10) after. However, since 32 percent (N=12) said they were unable to keep up with household chores before receiving the subsidy, some of these mothers could be included in the 26 percent enabled to keep up with household chores to a great or very great extent since receiving the subsidy.

With regard to other dimensions of family functioning and coping, there is little doubt as to the positive effects of the program when comparing before and after subsidy responses. For example, only six percent (N=2) of the respondents said they were able to purchase special items needed by the mentally handicapped child to a great or very great extent before receiving the subsidy, contrasted with 95 percent after receiving the subsidy. Similarly, only three percent (N=1) said they were able to purchase respite care to a great or very great extent before receiving the subsidy, contrasted with 71 percent after (N=27); do things with other family members, 16 percent (N=6) before, 58 percent (N=22) after; enjoy each other as a family, 26 percent (N=10) before, 55 percent (N=21) after; do things they enjoy outside the home, 11 percent (N=4) before, 61 percent (N=23) after; attend to needs of mentally handicapped child, six percent (N=2) before, 92 percent (N=35) after; and attend to needs of other family members, 16 percent before (N=6), 55 percent (N=21) after. Indeed, on a scale from

one to five, the overall mean family functioning score rose 2.4 points from 1.1 (s.d.=1.5) before families received the subsidy to 3.5 (s.d.=.85) after they received it. (See Table 4.)

 Insert Table 4 about here

While the MR Family Subsidy Program is unquestionably instrumental in enabling families to cope and function better and to care for their mentally handicapped child at home, the subsidy by no means covers all of the expenses entailed in the child's care for almost two-thirds of the families (63 percent, N=24). Such costs include medical expenses, 56 percent (N=13); medications, 87 percent (N=20); education, 82 percent (N=18); babysitting, 67 percent (N=16); respite care, 71 percent (N=15); special clothing, 67 percent (N=16); special food, 79 percent (N=15); special equipment, 71 percent (N=17); and transportation, 50 percent (N=13), even though such expenses are covered by the subsidy. Forty-four percent (N=12) said they find such expenses difficult to very difficult, 37 percent (N=10) said they find them somewhat difficult, and 19 percent (N=5) indicated they do not find them difficult at all. Those who find these expenses difficult, at least seven, pointed out that the \$250 ceiling remains fixed while expenses in caring for the child keep increasing. One mother also stated that the subsidy, by being limited to pre-established categories, precludes coverage for such expenses as long distance phone calls to consult with the child's doctor, explaining such expenses actually are cost-saving when compared to the

Table 4. Family Functioning and Coping Before and After Subsidy (N=38)

Family Functioning	no/small extent (1-2)		some extent (3)		great/very great extent (4-5)	
	Before %	After %	Before %	After %	Before %	After %
household chores	32	63	16	11	53	26
purchase items needed by MH child	89	3	5	3	6	95
purchase respite care	79	18	18	11	3	71
work outside home*	69	50	23	14	8	36
do things with other family members	61	26	24	16	16	59
enjoy each other as a family	42	29	32	16	26	55
do things enjoy at home	53	50	18	21	29	29
do things enjoy out of home	84	24	5	16	11	61
be with friends	58	26	21	18	21	55
attend to needs of MH child	68	3	26	5	6	92
attend to needs of other family members	61	26	24	18	16	55

*N=20 for before subsidy responses and 28 for after subsidy responses

expense of office visits to the doctor and attendant transportation costs.

When asked what they would do if they had a larger subsidy, most mothers had no difficulty in responding. Their shopping list includes the purchase of more of the same kind of services, such as respite care and babysitting; additional services, such as homemaker services, tutoring, and physical therapy for the child; additional items needed by the child, such as more clothes, special foods, educational toys, and recreational equipment; special equipment, such as a special chair, bathtub frame, ramp and van; better housing for the family; air conditioning for the child's allergies; and the replacement of household items damaged by the child. As one mother explained, she would use it for the child's needs without feeling other family members were being deprived of theirs.

Ratings of Subsidy Purchased Services and Other Family Resources

When asked to rate the services purchased by the MR Family Subsidy in terms of quality, availability, accessibility, convenience and cost, such services were rated very highly on all five counts. Indeed, comparing the overall mean ratings of subsidy purchased services with those of services provided by family and friends, and community agencies, subsidy purchased services were more highly rated than those provided by either family and friends or community institutions. For example, the overall mean rating for subsidy purchased services is 4.1 (s.d.=.8) while for community institutions, it is 3.9 (s.d.=1.1) and for family and friends, it is 3.6 (s.d.=1.01). Of particular interest is the fact that in terms of quality, substantially more respondents rated subsidy purchased services good to excellent (95 percent, N=36) than services

received from family and friends (78 percent, N=29), or community agencies (76 percent, N=29), although it is apparent that most families think the quality of services from all three sources is high. In terms of availability, both subsidy purchased services and community services are rated much higher than services from family and friends (74 percent, N=28; 71 percent, N=27; and 38 percent, N=14, respectively), with the same pattern holding for the accessibility criterion also: 68 percent (N=25) for subsidy purchased services; 63 percent (N=24) for community services; and only 40 percent (N=15) for services from family and friends. In terms of convenience, subsidy purchased services and services provided by community agencies were both rated good to excellent by 68 percent (N=26) of the respondents while only 35 percent (N=13) of the respondents rated services provided by family and friends good to excellent on this criterion. The pattern shifts a little in terms of cost with more respondents rating community services good to excellent, 84 percent (N=32), than services from family and friends, 81 percent (N=29) or subsidy purchased services, 79 percent (N=30). It is of more than passing interest to note that services provided by family and friends while rating high in terms of quality and cost apparently are not as available, accessible, or convenient for most of the study's families as subsidy purchased services or services provided by community agencies. (See Table 5.)

 Insert Table 5 about here

When asked about the extent to which families use specific services such as counseling and respite care, only a little over one third of the

Table 5. Family Ratings of Subsidy Purchased Services (SPS), Services Provided by Family and Friends (F&F) and Community Agencies (CA)*(N=38)

Service criteria	(1-2) Very poor/poor			(3) fair			(4-5) good/excellent		
	SPS	F&F %	CA	SPS	F&F	CA	SPS	F&F %	CA
quality	--	8	13	5	14	11	95	78	76
availability	11	35	13	16	27	16	74	38	71
accessibility	11	30	21	22	30	16	68	40	63
convenience	8	43	16	24	22	16	68	35	68
cost	19	9	13	3	11	3	79	81	84

*Percentages may not add to 100 because of rounding.

mothers (35 percent, N=13) stated they have used counseling services in relation to their mentally handicapped child to some or to a great or very great extent (24 and 11 percent respectively). Of those who have availed themselves of counseling services, over three-fourths (N=16) said such services were in the form of a support group in which they are able to share their feelings with other similarly situated families; 19 percent (N=4) use a psychologist or private physician and only one uses a mental health center for this purpose. As an aside, no one identified their county social service worker as a resource for this service even though it is through the social worker that most families learned about the Subsidy Program. Most (57 percent, N=12) found the counseling they received to be of great or very great help while 38 percent (N=8) found it to be of only some help; only one family found it to be of little or no help. On the average, the frequency with which families receive counseling is once every three or four months, although the frequency ranges from once a week to only very occasionally, less than once a year.

Interestingly, when asked about their use of respite care, only one third of the mothers (34 percent, N=13) indicated they use it to a great or very great extent with a surprising 37 percent (N=14) saying they almost never use it or use it to a very small extent. Those who do use it regard it as a great or very great help, 73 percent (N=25), with family members and hired babysitters being the most frequently used respite resources, 30 and 27 percent respectively (N=9 and 8). Only a few use such resources as foster homes (13 percent, N=4) or a residential treatment facility (10 percent, N=3) or the state hospital (3 percent, N=1) for this purpose.

Out of Home Placement Plans and Child's Development

Almost none of the families (97 percent, N=37) have ever placed their mentally handicapped child in long term care out of the home. The one family who had did so primarily because of the child's poor functioning and the stress involved in caring for him or her. The child subsequently returned home primarily because his or her functioning had improved and secondarily because the subsidy had become available, both of which helped to improve the family situation. Although only two families indicated they presently plan to place their child in long term care in a foster home or institution, one half of the families (N=19) surprisingly stated they anticipated making such plans in the future, even though most think their child has improved socially (68 percent, N=26), physically (71 percent, N=27), intellectually (58 percent, N=21), and emotionally (55 percent, N=21).

Almost all the families when asked (89 percent, N=34) said they think the program should be expanded to include young adults although one respondent felt the program should not be expanded while families with young children are waiting to get into the Program.

Suggestions for Improving Program

Although most respondents were generous in their praise of the Program, some did offer criticisms. For the most part, these revolved around procedural matters having to do with record keeping requirements, reapplication requirements, particularly their frequency, and in one case, the failure of the county social service worker to adequately inform participants about expenses covered by the program. The fact that

some socialization into the Program seems necessary before being able to know how to effectively participate in it is implied in the remark of one respondent who said at first she did not know what was expected of her or how to use the Program.

Suggestions for improving the Program followed from the criticisms. Such suggestions include the following:

1. Applications should be renewed every year instead of every six months.
2. Applications should be renewed by phone instead of in person.
3. The Program should be publicized better with information disseminated to hospitals, clinics, social workers and doctors who in turn should transmit such information to appropriate families.
4. Other parents should be used to publicize the program, especially to middle-class parents who tend to think public programs do not exist for them.
5. The subsidy should be increased on a case by case basis for those families whose consumption needs are greater, taking into account the fact that budgets often do not reflect family's actual circumstances.
6. Long distance telephone calls for medical consultation and out-of-home respite care for emergency situations should be covered by the subsidy.

Influences on Subsidy's Coping Effects

Criticisms and suggestions for improving the MR Family Subsidy Program must be seen in proper perspective. Clearly, most families find the program extremely helpful in enabling them to care for their mentally handicapped child at home and thus are able to manage and cope more effectively on almost all dimensions: psychologically, socially, and financially. Despite this, and while it is apparent that the subsidy enables most families to cope and cope more effectively with their situation, it does not enable others to do so to the same extent. The question is why. What variables serve to dampen or heighten the coping effects of the Subsidy Program on participating families? Also why is it that while almost none of the families indicated they presently plan to place their mentally handicapped child out of the home in long term foster or institutional care, one half (N=19) of them anticipate such placement in the future? Do those families who anticipate out of home child placement in the future differ significantly from those who do not? If so, in what ways?

To answer the question, what variables serve to dampen or heighten the coping effects of the Subsidy Program on participating families, a bivariate analysis was undertaken using Pearson's R to examine the relationship between the subsidy's coping effects, the study's major dependent variable, and the study's several independent variables: family size, composition, structure, family life cycle stage, socio-economic status, family resources, stressor pile-up, external environment, and the Subsidy Program itself in terms of the amount of subsidy families receive and the

length of time they have participated in the Program. The analysis shows the following to be moderately to extremely influential on the extent to which the Program enables families to care for their mentally handicapped child at home, one of the measures of the subsidy's coping effects:

age of oldest child, $r=.35$; father's educational attainment level, $r=-.41$; family annual income, $r=-.33$; severity of handicapping condition of other children in the family, $r=-.92$; and length of family participation in the program, $r=.37$. (See Table 6.) Clearly, the severity of the handi-

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Insert Table 6 about here

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capping condition of other children in the family has an extremely important dampening effect on this particular measure of the subsidy's coping effects, suggesting that the more severe the handicapping condition of other children in the family, the less effective the subsidy is in enabling families to cope with the care of their mentally handicapped child. The more moderate influence of family socio-economic status as measured by father's educational attainment level and annual family income and its negative direction suggests the extent to which the subsidy enables families to care for their mentally handicapped child at home is greater for families of lower socio-economic status, that is, as a resource, the subsidy is more helpful to them than it is to families of higher socio-economic status. At the same time, the moderate positive influence of family life cycle stage, as measured by age of oldest child, and the number of years families have participated in the Program suggest that these variables converge to enhance the subsidy's coping

Table 6. Influences on Coping Effects of MR Family Subsidy Program

	Care of Child at Home	Helpfulness of Subsidy	Family Functioning/ Coping Score	Change in Family Functioning/Coping
Family life cycle stage				
Age of oldest child	.35	---	---	.48
Age of youngest child	---	---	.37	.49
Age of handicapped child	---	---	---	.36
Socio-Economic Status				
Family annual income	-.33	---	---	---
Father's education	-.41	---	---	-.43
Stress Pile-Up				
Number of family life events	---	---	.39	.46
Severity/other child's handicapping condition	-.92	---	---	---
Child's developmental progress	---	---	.58	---
Family Resources				
Total resources available	---	-.37	---	---
Subsidy purchased services evaluation score	---	.37	---	---
Years of participation in Subsidy Program	.37	---	---	.38
Environmental conditions				
Median county income per tax filer	---	-.34	---	---

effects. Such convergence in part may be attributable to oldest children becoming a resource upon which families can draw as their children grow older at the same time that they become more familiar with the Program and how to use it the longer they participate in it, both phenomena increasing the coping effects of the subsidy.

Interestingly, with respect to perceived helpfulness of the Subsidy Program by participating families, another measure of the subsidy's coping effects, a different set of variables appear to be operative, although all are moderate in their influence. These include: resources available to families, $r=-.37$, ratings of subsidy purchased services, $r=.37$, and the economic environment of the county in which families reside, $r=-.34$. Thus, it would appear that the less affluent the county in which families reside and the fewer the resources available to them, the more helpful they perceive the Program, again suggesting the greater significance of the program to families in less advantageous circumstances. At the same time, the services families are able to purchase with the subsidy and their ratings of them apparently serve to enhance their perceptions of the helpfulness of the Program as a resource.

Still another set of variables are influential with respect to the coping effects of the subsidy in terms of family functioning and coping. These include: age of youngest child, $r=.37$, number of disruptive family events in the last six months, $r=.39$, and the mentally handicapped child's developmental progress, $r=.58$, all moderately to quite strongly positive in direction. Thus, the subsidy's effects on family functioning and coping are enhanced as youngest children grow older, thereby making fewer

physical demands on mothers, and by the developmental progress of the mentally handicapped children. Further, because family life events often have serious economic implications for families whether they involve a job change or loss, a serious illness, or a divorce, the subsidy's effects on family functioning and coping apparently are enhanced by the subsidy's ability to mitigate the economic hardships accompanying such life events.

With respect to change in family functioning and coping that may be attributable to the Subsidy Program, most of the same variables not surprisingly reappear as influential, in most cases, more strongly. These include ages of oldest and youngest child, $r=.48$ and $.49$ respectively, as well as age of mentally handicapped child, $r=.36$, the latter appearing as an influence for the first time. All suggest a convergence of Program and family life cycle effects, namely that as children grow older, the change effects of the Subsidy Program on families' coping and functioning capacities are enhanced. Other influences on the change effects of the Subsidy Program on family coping and functioning include father's educational attainment level, $r=-.43$, number of disruptive family life events in the last six months, $r=.46$, and length of time families have participated in the program, $r=.38$. Such influences again suggest the greater significance and meaning of the Program to families in less advantaged circumstances and the importance of the Program in enabling families to cope with stressful life events. Again, length of time families have participated in the Program appears influential, this time to enhance the subsidy's change effects on family functioning and coping.

Clearly, family variables, family life cycle stage, in particular, but also family socio-economic status, family life events, family resources, stressor pile-up, and family socialization into the Program, all serve to influence the coping effects of the Subsidy Program on families participating in it. While stressor pile-up in terms of the severity of the handicapping condition of other children in the family and the mentally handicapped child's lack of developmental progress serve to dampen its effects, the other variables heighten them: family life cycle stage in terms of ages of oldest, youngest, and mentally handicapped child; family socialization in terms of length of family participation in the Program; and recent disruptive family life events being positively related to the subsidy's coping effects, and family resources and economic environment being negatively related. Interestingly, the amount of the subsidy does not show an influence on any of the measures of the subsidy's coping effects, as might have been expected, while years of program participation does, suggesting that the amount of the subsidy apparently is not as important as its availability, although over two-thirds of the families participating in the study receive the maximum subsidy of \$250. It is also of some interest that except for economic environment, none of the other environmental variables such as community attitudes toward mental retardation, county population, or political constituency for mental retardation programs had an affect on the coping effects of the subsidy or on other variables, such as family resources or subsidy purchased resources, or family ratings of such resources.

Families Planning Out-of-Home Placement

To examine the question: Do families who anticipate placing their mentally handicapped child out of the home in foster or institutional

care differ significantly from those who do not and if so, in what ways, a two sample t test was undertaken with respect to variables initial analysis suggested as being potentially influential. These included family size, number of children living at home, ages of mother, father, and oldest child, mother's employment status, developmental progress of the mentally handicapped child, and severity of the handicapping condition of other children in the family. Indeed, the two groups were found to differ significantly from each other on many of these variables, namely, family size ($t=-2.15$, $p=.04$, $d.f.=31$); employment status of mother ($t=-3.40$, $p=.002$, $d.f.=26$), mother's age ($t=-2.50$, $p=.02$, $d.f.=31$), and developmental progress of child ($t=-2.41$, $p=.02$, $d.f.=33$). They did not differ from each other significantly with respect to fathers' age or age of oldest child, however. Because of the small number of other children in the family with a handicapping condition, the two sample t test could not be performed on this variable. At the same time, a frequency analysis shows that four of the six families having other children with a handicapping condition do not anticipate placing their mentally handicapped child out of the home. (See Table 7.)

 Insert Table 7 about here

With respect to family size, the mean number of children for families planning to place their mentally handicapped child out of the home is 2.68, $s.d.=1.20$; for those not anticipating out of home placement for their child, the mean number of children is 3.7, $s.d.=1.76$, suggesting that families with fewer children are more likely to anticipate out of home

Table 7. Differences between Families Planning and Not Planning to Place Child out of Home

	Family Size	Mother Work	Mother Age	Child Progress
1. Place out of home N = 19	$\bar{x} = 2.68$ s.d. = 1.20	$\bar{x} = 2.05$ s.d. = .85	$\bar{x} = 4.05$ s.d. = .91	$\bar{x} = 1.95$ s.d. = 1.58
2. Not Place N = 19	$\bar{x} = 3.73$ s.d. = 1.76	$\bar{x} = 2.79$ s.d. = .42	$\bar{x} = 5.00$ s.d. = 1.37	$\bar{x} = 3.05$ s.d. = 1.22
Degrees of Freedom	31	26	31	33
T Value	-2.15	-3.40	-2.50	-2.41
Significance Level	.04	.002	.02	.02

placement for their mentally handicapped child than those with more children.

With respect to mother's employment status, the mean for those planning to place their mentally handicapped child out-of-the-home is 2.05 with a s.d.=.85, while the mean for those not planning to place their child out of the home is 2.79 with a s.d.=.42, suggesting that families in which mothers are employed outside the home are more likely to anticipate long term out of home placement for their mentally handicapped child than those who are not. Indeed, all of the families in which mothers work full time outside the home (N=6) and two-thirds of those who work part time (N=6) anticipate placing their child out-of-the-home.

With respect to mothers' age, the mean age for those who anticipate placing their mentally handicapped child out of the home is 4.05, s.d.=.91, while for those who do not, the mean is 5.0, s.d.=1.37, about a five year difference between the two groups. This suggests that families with younger mothers are more likely to anticipate placing their mentally handicapped child out of the home than families with older mothers.

With respect to the mentally handicapped child's developmental progress, the mean for families intending to place their mentally handicapped child out of the home is 1.95, s.d.=1.58, while for those who do not anticipate out of home placement, the mean is 3.05, s.d.=1.22, indicating that families whose mentally handicapped child shows less progress developmentally are more likely to anticipate out of home placement for the child than those whose child shows more developmental progress, which should not be altogether surprising.

How should such data be read? What do they mean? The findings that families with younger mothers, working mothers, and fewer children are more likely to anticipate placing their mentally handicapped child out of the home than families with older mothers, unemployed mothers, and more children requires consideration of some of the data previously presented. Despite the fact that in most families, children do not assume a primary caretaking role vis-a-vis the handicapped child, the data show that children are a helpful resource for their families, particularly as they grow older. It could be that smaller families by their very nature are deprived of the advantages of larger families in terms of the availability of children as helping resources. Family size not only is a function of cultural norms and economics, but also mothers' age and family life cycle stage. It takes time, in fact years, to bear children and rear them to the point where they are able to contribute to family functioning in the form of rendered services. Younger mothers, by virtue of their age, have not had time to acquire the benefits of such helping resources as a return on earlier investments of time, energy and money. Further the current norm of smaller families means that younger mothers are not apt to ever acquire such resources. In addition, it has become increasingly common for mothers of young children to work outside the home. A different set of cultural norms dominated the lives of older mothers when they were in their early child bearing, child rearing stages of the family life cycle, norms that required them to be full time homemakers and mothers of large families, roles into which they now are firmly entrenched and which are reinforced by a labor market biased against older workers. Thus, younger mothers

more than older mothers are likely to perform dual roles of family caretakers and workers in the labor force. In the case of younger mothers with a mentally handicapped child, the performance of these dual roles, while increasingly common and only somewhat conflictual under ordinary circumstances, may prove too burdensome, too conflictual, and too stressful in their circumstances, particularly when their mentally handicapped child does not show developmental progress. Perhaps the multiplicity of roles and the shortage of systemic resources to help them mesh the competing demands of these roles with the special needs of their child account for the findings that younger mothers, mothers who work outside the home, and mothers who have fewer children are more likely to anticipate the long term out of home placement of their mentally handicapped child than older mothers, mothers who stay at home, and mothers who have larger families. To test such speculations, further research would need to be conducted looking separately at older and younger mothers in relation to their plans for the long term care of their mentally handicapped child, controlling for family size, mothers' employment status and child's developmental progress simultaneously. To conduct such research, a relatively large sample of families would be needed, much larger than that of the present study.

SUMMARY AND CONCLUSIONS

In summary, to answer the study's questions, what are the coping effects of the MR Family Subsidy Program on families with a severely mentally handicapped child, the study's findings show that the coping effects of the subsidy are considerable on all of the measures used: 1) enabling families to care for their mentally handicapped child at home; 2) degree of general helpfulness of the subsidy to families; 3) families' functioning and coping capacities, financial, social and psychological; and 4) changes or improvements in families' functioning and coping capacities, financial, social and psychological. In terms of family functioning and in order to descending frequency, the subsidy in particular enables mothers as the child's primary caretaker to: 1) purchase items needed by the child; 2) attend to the mentally handicapped child's needs; 3) purchase respite care and babysitting services for the child; 4) do things outside the home they enjoy; 5) do things with other family members; 6) enjoy the company of family members; 7) be with friends occasionally; and 8) attend to the needs of family members. Dimensions of family functioning on which the subsidy seems to have had the least effect include: 1) enabling mothers to work outside the home; 2) do things at home they enjoy; and 3) keep up with household chores, all activities that compete with the needs of the mentally handicapped child and family members for mothers' time and energies. At the same time, it should be noted that although the Subsidy Program has not had a tremendous effect on the employment status of the study's mothers, it has enabled some mothers to work outside th home. The dimensions on

which the subsidy has effected the greatest improvement in family functioning and coping include the purchase of special items needed by the child, the purchase of respite care and babysitting services, and attending to the child's needs. Thus, the program is doing what it was hoped it would do, what it is intended to do, and doing both very well indeed.

Families' satisfaction with the Program carries over to the services and items the subsidy purchases, the two interacting in reinforcing ways. That is, because mothers perceive the Program in such a favorable light and are so strongly committed to it, they regard the services and items they purchase with it in a similarly favorable light, suggestive of the influence of perceptions on affective judgements and the way in which the two achieve congruency. When asked, for example, what they liked least about the Program, many said "Nothing;" when asked what they liked best about it, many said, "Everything." Many specifically referred to the psychological and financial security the subsidy affords them, thereby reducing the stress involved in the care of their mentally handicapped child and the expenses such care requires. However, the fact that the subsidy is not sufficient to cover many of the expenses involved in the child's care and is limited to pre-established expense categories creates difficulties for many of the families, despite the fact that two-thirds are receiving the maximum monthly subsidy of \$250.

This suggests that despite its extremely positive effects on families' capacities to cope with the care of their mentally handicapped child and to function as a family, such effects are greater for some families than for others. Variables that seem to heighten these effects include: family life

cycle stage as measured by ages of oldest, youngest, and mentally handicapped child; the child's developmental progress; length of family participation in the Program; number of recent disruptive family events and family circumstances in terms of socio-economic status, family resources, and family economic environment. With regard to the latter set of variables incorporated under the rubric of family circumstances, there is an inverse relationship between each of these variables and the subsidy's coping effects, which is consistent with the positive affects of number of recent disruptive family life events on the subsidy's coping effects. That is, the lower the family's socio-economic status, the greater number of disruptive family life events it experienced in the last six months, the fewer internal and external resources available to it, and the less affluence the county in which the family resides, the greater the coping effects of the subsidy. In other words, for families experiencing multiple stressors, or stress pile-up, the subsidy's coping effects are even greater than they are for other families in the study. Case studies which offer the opportunity to pursue the examination of issues in greater depth would be useful in examining the implications of these findings, particularly in conjunction with a larger survey that would allow for the simultaneous examination of interacting variables. Such findings should in no way be construed to suggest that the Program be modified in terms of income conditioning or more precise program targeting. Such modifications would distort the Program's primary intent of enabling families to care for their mentally handicapped child at home. Further, given the unpredictability of family circumstances, families in more fortunate circumstances today may be in less fortunate circumstances tomorrow. For the study's families, restrictions in program eligibility or reductions in the subsidy, could be a factor in changing

their circumstances in ways that could seriously damage their coping capacities and thus their ability to care for the mentally handicapped child at home.

That family life cycle stage, as measured by children's ages, converges with the Program's effects in ways that heighten or increase them also should be examined in greater depth in subsequent research, especially since family life cycle stage has shown itself to be such an important variable in other policy studies as well (Bishop, 1977; Bradbury, 1977). With respect to the present study, such effects have been interpreted in terms of the greater resources families have available for assisting them with the care of their mentally handicapped child coupled with the decreased demands placed on parents' time and energies as children grow older, thereby supporting the coping effects of the Program.

The influence of the length of family participation in the Program which could be defined in terms of the developmental stage of the Program as well as in terms of families' socialization into the Program might be explained by the fact that as families gain experience in the Program over time, they are better able to use it in ways that increase its coping effects. Thus, consistent with other studies examining the influence of program use (Zimmerman, Mattessich and Leik, 1979), the longer families participate in the Subsidy Program, the greater the subsidy's coping effects. Again, further exploration into ways in which length of Program use acts upon families to increase its effects would be enlightening, not only with regard to this study but other policy studies also.

The finding that the child's developmental progress converges to enhance the subsidy's coping effects is hardly surprising. Indeed, it

would have been surprising if it had not. As a corollary, however, when the child does not progress developmentally, the subsidy's coping effects would necessarily be dampened. For this reason, it also is not surprising that the severity of the handicapping condition of other children in the family similarly serves to dampen the coping effects of the subsidy. However, the extent to which it does so is surprising, $r = -.92$. Although the data are insufficient to determine whether such effects extend to future family decisions with respect to the out of home placement of the mentally handicapped child, they merit serious attention in any future study on this subject. In the meantime, it may be well to take these data into account in any future deliberations relative to the Subsidy Program.

With respect to the prospective out of home placement of the mentally handicapped child, the findings that younger mothers, mothers who work outside the home, mothers who have fewer children, and mothers whose mentally handicapped child shows less developmental progress are more likely to anticipate out of home child placement than their opposites are consistent with prevailing norms. Both because labor force participation by mothers of young children has become acceptable practice and because of labor force bias against older workers, younger mothers are more likely to be employed outside the home than older mothers. Thus, younger mothers not only are more likely to perform dual family and work roles than older mothers, but also are more likely to have fewer resources available to them in the form of older children's services, in part as a function of current norms for smaller families and in part as a function of the timing of their family life cycle stage. That is, the interest

and dividends on their child bearing, child rearing investments have not had time to accrue in the form of services that older children can provide. As the study indicates, older children, although they do not assume a primary caretaking role vis-a-vis the mentally handicapped child, a role that mothers perform with the assistance of fathers, they nonetheless are identified as a valuable helping resource. Current norms for smaller families suggest that this generation of younger mothers may always be somewhat disadvantaged in this regard. Clearly, an important question in any future research on this subject must concern itself with the effects of mothers' labor force participation and small families on the long term capacities of families to care for handicapped and chronically ill members at home. To the extent the Subsidy Program facilitates mothers' employment outside the home, the question could legitimately be asked whether or not the Program has unintentional cross-purpose effects. Special note should be taken that families' anticipated long term plans for their child are unaffected by the subsidy's coping effects. In other words, family decisions with respect to the long term care of their mentally handicapped child are independent of the subsidy. This means that the Subsidy Program, like all such programs, cannot be expected to overcome strong countervailing family influences.

Finally, the important linkage role of social workers in providing information to families about the Program needs to be underscored, and obviously needs to be strengthened. Because of the complexity of the organizational system in which the role is performed and the uncertainty that information transmitted by the State agency through its usual communi-

cation channels actually reaches and is received by all of the social workers interacting with families in the 85 county social service agencies supervised by the State agency, the linkage role of the social worker becomes somewhat problematic. This means that the social worker cannot be relied upon to be the only linkage mechanism connecting families to the Program, despite attempts that may be made to strengthen the worker's role in this regard. Therefore, multiple channels of communication need to be developed and opened to provide multiple channels of access for families via information about it into the Program. Because society via the state increasingly is coming to rely on families to perform critical long term service functions for members unable to care for themselves, it is in society's best interests to not only provide such valuable resources as the MR Family Subsidy Program to strengthen the coping capacities of affected families, but to assure information about such resources reaches them as well.

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STATE OF MINNESOTA
DEPARTMENT OF PUBLIC WELFARE
CENTENNIAL OFFICE BUILDING
ST. PAUL, MINNESOTA 55155

OFFICE OF THE
COMMISSIONER
612/296-2701

GENERAL
INFORMATION
612/296-6117

PLEASE REPLY TO _____

• September 17, 1982

Dear

You are invited to participate in a study concerning the MR Family Subsidy Program in which your family is participating.

This study is being conducted by Dr. Shirley Zimmerman, Assistant Professor in the Department of Family Social Science at the University of Minnesota. It is being funded by the Developmental Disabilities Section, which is a part of the Minnesota State Department of Energy, Planning, and Development. The Minnesota Department of Public Welfare is a cooperating agency.

The purpose of the study is to learn if and how the MR Family Subsidy Program is helpful to you and other families participating in this Program. Your name was randomly selected by me from the families now receiving grants under this Program.

The findings of this study will be especially helpful in guiding the planning and programming efforts of the cooperating agencies. They also will be helpful in leading to a better understanding of the families in this Program.

The study will be conducted through telephone interviews with the mothers of the selected families, as mothers generally are the ones who assume primary responsibility for the personal care of the family members. If this is not true for your family, then the interview will be conducted with the family member who assumes such responsibility. The interviewers will all be professional personnel.

The interviews will take from one-half hour to an hour to complete. They will be scheduled between 6:30 p.m. and 9:30 p.m. in the evenings Monday through Thursday. These interviews will begin about October 1 and end about November 1. If either the evening hours or the weeknights are inconvenient for you, you may arrange an interview at some other time. Please indicate on the enclosed consent form your first, second, and third preferences for the interview. This consent form should be signed by you as the family's primary caregiver or by the family member who assumes that role. It should be returned in the enclosed stamped, addressed envelope.

Page Two
Mr. and Mrs. Sweeny
September 17, 1982

It is important that you respond within one week.

Individual responses will be kept strictly confidential and no respondent will be identified by name in the study's report. A summary of the findings of the study will be mailed to participating families.

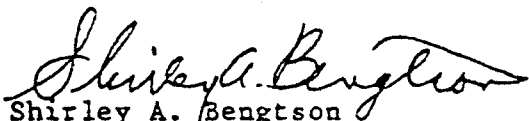
You, of course, are free not to participate in this study. In that event, please so indicate by checking the designated space on the consent form, signing your name, and returning it to Dr. Zimmerman within one week.

Your participation or lack of participation will have no effect on your continuing MR Family Subsidy grant.

If you have any questions about the study or about your participation in it, please call Dr. Zimmerman at 612/376-5694. If she is not in, you may leave your name and phone number at 612/373-1578 and she will return your call as soon as possible. You also may call me about this study at 612/296-2168.

Thank you in advance for your anticipated interest, time, and cooperation in this effort.

Sincerely,



Shirley A. Bengtson
MR Family Subsidy Supervisor
Assistant Director, MR Division

HT-02

Enclosure

CONSENT FORM FOR MR FAMILY SUBSIDY PROGRAM STUDY

I understand that my participation in this study is entirely voluntary and that my responses will be kept in strict confidence.

Please check appropriate response:

I will participate in the study ☐

I will not participate in the study ☐

If you will be participating in this study, please indicate the weeknight you would prefer to be interviewed according to your first, second and third choices. Interviewing will begin about October 1 and end about November 1.

Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐

Other (please specify) _____

For clerical and for interviewers' use only:

Signature _____

Address _____

Telephone Number (include area code) _____

Please complete this form and return it within one week to:

Dr. Shirley Zimmerman
Family Social Science
University of Minnesota
290 McNeal Hall
1985 Buford
St. Paul, MN 55108

THE EFFECTS OF THE MR FAMILY SUBSIDY PROGRAM ON FAMILIES OF MENTALLY HANDICAPPED CHILDREN

Child's name receiving subsidy _____ Interviewer's name _____

Please not: Follow coding instructions throughout. Place the actual or coded number of the most appropriate response in the space provided beside each item.

3. _____ Marital status Code: 1) married 3) divorced or separated 5) never married
 2) remarried 4) widowed
4. _____ Number of children in family (write in actual number but for 9 or more, code 9)
5. _____ Number of children living at home (write in actual number but for 9 or more, code 9)
6. _____ Number of step children living at home, if remarried (write in actual number, but coding as above)
7. _____ Number of parents living at home (write in actual number)
8. _____ Employment status Code: 1) full time 2) part time 3) unemployed
9. _____ Spouse's employment status (use same code as item 8)
10. _____ Respondent's age Code: 1) 20 or under 4) 31 to 35 7) 46 to 50
 2) 21 to 25 --5) 36 to 40 - 8) 51 to 60
 3) 26 to 30 6) 41 to 45 9) 60 plus
11. _____ Spouse's age (use same code as item 10)
12. _____ Age of oldest child Code: 1) 0 to 1 4) 10 to 12 7) 22 to 29
 2) 2 to 4 5) 13 to 17 8) 30 to 39
 3) 5 to 9 6) 18 to 21 9) 40 plus
13. _____ Age of youngest child Code: 1) 0 to 1 3) 5 to 9 5) 13 to 17
 2) 2 to 4 4) 10 to 12 6) 18 to 21
14. _____ Age of mentally handicapped child (use same code as item 13)
15. _____ Number of girls in family (write in actual number but for 9 or more, code 9)
16. _____ Number of boys in family (write in actual number but for 9 or more, code 9)
17. _____ Sex of mentally handicapped child Code: 1) girl 2) boy
18. _____ Respondent's highest level of educational attainment
 Code: 1) less than high school 5) some graduate work
 2) high school 6) master's degree
 3) some college 7) some post master's work
 4) BA degree 8) PH.D
19. _____ Spouse's highest level of educational attainment (use same code as item 18)

20. _____ Family's approximate annual income
Code: 1) \$5000 or less 4) \$15000 to \$19000 7) \$30000 to \$39000
2) \$5000 to \$9000 5) \$20000 to \$24000 8) \$40000 to \$49000
3) \$10000 to \$14000 6) \$25000 to \$29000 9) \$50000 and over

21. _____ Respondent's health Code: 1) very poor 2) poor 3) fair 4) good 5) excellent

22. _____ Spouse's health (use same code as item 21)

23. _____ Health of other children in family overall (use same code as items 21 and 22)

24. _____ Do other children living at home have a handicapping condition? Code: 1) yes 2) no

If yes, on a scale from 1 to 5, to what extent does that child's handicapping condition affect his or her ability to: (1 is to absolutely no extent and 5 is to a very great extent)

25. _____ toilet him or herself

26. _____ walk by him or herself

27. _____ see

28. _____ hear

29. _____ play with other children

30. _____ relate to adults

31. _____ other, please specify _____

Using the same rating scale, to what extent does your mentally handicapped child's condition affect his or her ability to:

32. _____ toilet him or herself

33. _____ walk by him or herself

34. _____ see

35. _____ hear

36. _____ play with other children

37. _____ relate to adults

38. _____ other, please specify _____

39-40. _____ Who in the family assumes most of the responsibility for caring for your mentally handicapped child in addition to you?

Code: 01) spouse	05) spouse's father	09) spouse's sister
02) mother	06) daughter	10) brother
03) spouse's mother	07) son	11) spouse's brother
04) father	08) sister	12) a family friend

41. _____ If that member is a son or daughter, is he or she older than your mentally handicapped child?
Code: 1) yes 2) no

42. _____ Who in the family assumes the least responsibility for caring for your mentally handicapped child? (use same code as item 39-40)

44. _____ If that member is a son or daughter, is he or she younger than your mentally handicapped child?
Code: 1) yes 2) no

Have you or any member of your immediate family experienced any of the following during the last six months Code: 1) yes 0) no

45. _____ death of a family member

46. _____ a serious illness

47. _____ loss of a job

48. _____ divorce or separation

49. _____ birth of a child

- 50. _____ remarriage
- 51. _____ adoption of a child
- 52. _____ return of an absent member
- 53. _____ job change
- 54. _____ serious disability
- 55. _____ a large loss of income
- 56. _____ a large increase in income
- 57. _____ difficulty with the law
- 58. _____ institutionalization

Now I would like to get some of your reactions to the MR Family Subsidy Program.

59. _____ On a scale from 1 to 5, to what extent has the MR Family Subsidy Program enabled you to care for your mentally handicapped child at home? (1 is to absolutely no extent and 5 is to a very great extent)

Using the same scale, to what extent would you say the Family Subsidy has helped you and your family in terms of being able to:

- 60. _____ keep up with household chores, such as meal preparation, laundry and cleaning
- 61. _____ purchase special services or items needed by mentally handicapped child
- 62. _____ hire baby sitters or purchase respite care
- 63. _____ work outside the home
- 64. _____ do things with other children or spouse
- 65. _____ enjoy each others' company as a family
- 66. _____ do things at home, such as sewing, cooking, gardening, for fun
- 67. _____ do things outside the home, such as going to movies, walking, and so forth
- 68. _____ be with friends occasionally
- 69. _____ attend to needs of mentally handicapped child
- 70. _____ attend to needs of other family members

Again, using the same rating scale, before you received the Family Subsidy, to what extent would you say you were able to:

- 71. _____ keep up with household chores
- 72. _____ purchase special services or items need by mentally handicapped child
- 73. _____ hire baby sitters or purchase respite care
- 74. _____ work outside the home
- 75. _____ do thing^s with other children or spouse
- 76. _____ enjoy each other's company as a family
- 77. _____ do things at home, such as sewing, cooking, gardening, for fun
- 78. _____ do things outside the home, such as going to movies, walking, and so forth
- 79. _____ be with friends occasionally
- 80. _____ attend to needs of mentally handicapped child

Card #2

1

ID#

2-3

4. _____ attend to needs of other family members

Are there expenses related to the care of your mentally handicapped child the subsidy does not cover? Code: 1) yes; 2) no

If yes, what kinds of expenses are they? Code: 1) yes; 2) no

- 6. _____ medical expenses
- 7. _____ medications
- 8. _____ education
- 9. _____ baby sitting
- 10. _____ respite care
- 11. _____ special clothing
- 12. _____ special food
- 13. _____ special equipment
- 14. _____ transportation
- 15. _____ individual or family counseling
- 16. _____ homemaker service
- 17. _____ home remodeling for mentally handicapped child
- 18. _____ other, please specify _____
- 19. _____ other, please specify _____

20. _____ On a scale from 1 to 5, how difficult are these expenses for you, 1 being not at all difficult and 5 being very difficult?

On a scale from 1 to 5, to what extent do you receive help in caring for your mentally handicapped child from: (1 is to absolutely no extent and 5 is to a very great extent)

- 21. _____ your parents
- 22. _____ your spouse's parents
- 23. _____ your children
- 24. _____ your sister(s)
- 25. _____ your brother(s)
- 26. _____ your husband's sister(s)
- 27. _____ your husband's brother(s)
- 28. _____ friends
- 29. _____ church or synagogue
- 30. _____ county welfare department
- 31. _____ mental health center
- 32. _____ public health department
- 33. _____ public schools
- 34. _____ day activity center
- 35. _____ state hospital
- 36. _____ other, please specify _____

37. _____ Are fees or charges connected with the help you receive from any of these sources?
Code: 1) yes; 2) no

38. _____ Are these fees or charges covered by the MR Family Subsidy Program? Code: 1) yes; 2) no

Overall, on a scale from 1 to 5, how would you rate the services and other provisions you are able to purchase with the Family Subsidy in terms of: (1 is very poor and 5 is excellent)

- 39. _____ quality
- 40. _____ availability
- 41. _____ accessibility
- 42. _____ convenience
- 43. _____ cost

Overall, using the same rating scale, how would you rate the services and provisions you receive from family and friends in terms of:

- 44. _____ quality
- 45. _____ availability
- 46. _____ accessibility
- 47. _____ convenience
- 48. _____ cost

Again, using the same rating scale, how would you rate the services and provisions you receive from community agencies and institutions such as the county welfare department, the mental health center, the public health department and the public schools, overall, in terms of:

- 49. _____ quality
- 50. _____ availability
- 51. _____ accessibility
- 52. _____ convenience
- 53. _____ cost

54. _____ On a scale from 1 to 5, to what extent do you or have you ever received counseling in relation to your mentally handicapped child? (1 is to absolutely no extent and 5 is to a very great extent)

55. _____ What resource do you use the most for counseling services?

- | | |
|------------------------------------|------------------------------|
| Code: 1) county welfare department | 4) private practitioner |
| 2) day activity center | 5) other, what or who? _____ |
| 3) mental health center | |

56. _____ On a scale from 1 to 5, how helpful has such counseling been to you? (1 is of absolutely no help and 5 is of very great help)

57. _____ About how often do you see your counselor or worker?

- | | |
|----------------------------|----------------------|
| Code: 1) every week or two | 4) every 6 months |
| 2) once a month | 5) once a year |
| 3) every 3 to 4 months | 6) practically never |

58. _____ On a scale from 1 to 5, to what extent do you use respite care? (code using same rating scale as item 54)

59. _____ What resource do you use the most for respite care?

- | | |
|-----------------------------------|------------------------------|
| Code: 1) state hospital | 5) friends |
| 2) foster home | 6) hired baby sitter |
| 3) residential treatment facility | 7) other, who or what? _____ |
| 4) family | |

60. _____ On a scale from 1 to 5, how helpful has such respite care been to you? (code using same rating scale as item 56.)

61. _____ Have you ever place^d your mentally handicapped child out of the home in long term care in a foster home or institution? Code: 1) yes 2) no

If yes, on a scale from 1 to 5, to what extent did the following reasons contribute to your decision to place your child out of the home in long term care? (code using the same rating scale as item 54)

- 62. _____ child's poor functioning
- 63. _____ needs of other children in family
- 64. _____ stress of constant care of child
- 65. _____ money
- 66. _____ the need for employment outside the home
- 67. _____ other, what? _____

Using the same rating scale, to what extent did any of the following reasons contribute to your decision to have your mentally handicapped child return to the home? (code using the same rating scale as items 54 and 62 through 67 on card 2)

68. _____ child improved
69. _____ family situation improved
70. _____ MR family subsidy became available
71. _____ other, what? _____
72. _____ Do you presently have plans to place your child out of the home for long term care in a foster home or institution? Code: 1) yes 2) no
73. _____ Do you anticipate having such plans in the future? Code: 1) yes 2) no
74. _____ On a scale from 1 to 5, how helpful do you think the MR Family Subsidy Program has been to you and your family? (1 is of absolutely no help and 5 is of very great help)
- Do you think your child has progressed faster than what might have been expected without the family subsidy? Code: 1) yes 0) no
75. _____ socially
76. _____ physically
77. _____ intellectually
78. _____ emotionally
79. _____ Do you think the Program should be expanded to include young adults? Code: 1) yes 2) no
80. _____ How did you first learn about the Program?
- | | |
|-------------------------------|--------------------------------|
| Code: 1) county social worker | 5) other program participants |
| 2) friend | 6) Ass'n for Retarded Citizens |
| 3) family member | 7) word of mouth |
| 4) newspaper article | 8) other, how? _____ |

Card #3 _____
1

ID# _____
2-3

4. _____ After applying, how long did you have to wait to be accepted into the Program?
- | | |
|----------------------|---------------------|
| Code: 1) a few weeks | 4) 8 to 12 months |
| 2) 2 to 3 months | 5) more than a year |
| 3) 4 to 7 months | |

GO TO NEXT PAGE

Interviewers: Do not code responses to the following q
of the responses.

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appendix
ONLY

1. If you had a larger subsidy, what would you do with it?

2. What do you like best about the Subsidy Program?

3. What do you like least about the Subsidy Program?

4. What suggestions do you have for improving it?

Thank you very much for your help and time.

APPENDIX D

THE EFFECTS OF THE MR FAMILY SUBSIDY PROGRAM ON FAMILIES OF MENTALLY HANDICAPPED CHILDREN

Instructions to Interviewers

This study is being conducted to examine the effects of the MR Family Subsidy Program on families with mentally handicapped children. The program is not to be confused with other financial assistance programs such as AFDC. It is only for families with severely mentally retarded children to enable them to keep their children at home. The study is being funded by the Developmental Disabilities Section of the Minnesota Department of Energy, Planning, and Development and is being conducted in cooperation with the Minnesota Department of Public Welfare. Dr. Shirley Zimmerman, Ass't Professor in the Department of Family Social Science at the University of Minnesota, is the principal investigator of the study.

The study is being conducted to obtain information from families participating in the Subsidy Program that will help guide the planning and programming efforts of the sponsoring agencies, and also to obtain information that will lead to a better understanding of the families in the Program and their problems.

Families invited to participate in the study were randomly selected from a list of families participating in the MR Family Subsidy Program maintained by Shirley Bengtson at the Minnesota Department of Public Welfare who directs the Program. Individual responses will be kept confidential. No one will be identified by name. Participation is voluntary. No family's Program status will be jeopardized by choosing not to participate. Participating families will receive a summary of the findings when the study has been completed. Most families you will be interviewing will have previously agreed to participate in the study by signing a consent form in response to a letter they received from Shirley Bengtson.

Begin the interview by asking for the person whose name is on the attached list. Usually that person will be the mother of the mentally retarded (MR) child for whom the subsidy is given.

Introduce yourself by name and explain your role in the study. Tell mother that the interview will take a half to an hour to complete. Assure her that all responses will be kept confidential and be willing to share any of the above information with her about the study.

Ask if this is a good time to conduct the interview. If not, arrange to talk at another mutually agreed upon time within the week.

Please note. Although this is a structured questionnaire, it is meant to be used more as an interview guide. Do not read all of the coded responses. Very often respondents will provide the information you want without an item by item reading, although you may have to guide them in structuring their responses to be consistent with the framework of the study. Follow coding instructions throughout.

Use the child's actual name in questions referring to him or her. Where the word "spouse" appears in questions, use the word "husband" or "wife", depending on whether the respondent is the husband or wife.

When an item or set of items does not apply, such as in "If yes" kinds of questions, go on to the next question or set of questions. Leave spaces blank when questions are not applicable to the situation.

Open ended questions at the end of the questionnaire are not to be coded. Be succinct in the recording of responses, getting their essence, not their elaborations.

Be friendly and put the parent at ease. The ease with which you conduct the interview will depend on your familiarity with the questionnaire and the study's purposes. Be brief. No interview should take more than an hour. If you have any questions, call me right away: 926-8644, home; 373-5694, FSS office; 373-1578, CESW office; and 373-1578, FSS main office. You can leave messages at the latter two numbers.

We are working within tight time constraints. Return completed questionnaires to me weekly until done. Code legibly with dark sharp pencil.

ID# _____ Name _____

Information to be gathered from public records.

- 5-6. _____ county of residence
- 7-8-9-10-11-12. _____ county population
- 13-14-15-16-17. _____ county median income per tax filers
- 18-19-20-21. _____ number of MR wards living in county
- 22-23-24-25-26. _____ proportion of MR wards living in county relative to county population
- 27-28-29. _____ number of MRs from county residing in state hospitals
- 30-31-32-33-34. _____ proportion of MRs from county residing in state hospital relative to county population
- 35-36-37-38. _____ total number of MR beds in county
- 39-40-41-42-43. _____ proportion of MR beds relative to county population
44. _____ number of years family has participated in program
- 45-46-47. _____ amount of subsidy family presently receives

Family's subsidy expenditures Code: 1) yes 0) no

48. _____ medical expenses
49. _____ medications
50. _____ education
51. _____ baby sitting
52. _____ respite care
53. _____ special clothing
54. _____ special diet
55. _____ special equipment
56. _____ transportation
57. _____ camp
58. _____ other, what? _____